



**QUEEN'S
UNIVERSITY
BELFAST**

Oesophageal cancer: caregiver mental health and strain

Donnelly, M., Anderson, L. A., Johnston, B. T., Watson, R. G. P., Murphy, S. J., Comber, H., McGuigan, J., Reynolds, J. V., & Murray, L. J. (2008). Oesophageal cancer: caregiver mental health and strain. *Psycho-oncology*, 17(12), 1196-1201. <https://doi.org/10.1002/pon.1337>

Published in:
Psycho-oncology

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

Oesophageal cancer: caregiver mental health and strain

M. Donnelly^{1*}, L.A. Anderson¹, B.T. Johnston², R.G.P. Watson², S.J. Murphy³, H. Comber⁴, J. McGuigan², J.V. Reynolds⁵ and L.J. Murray¹

¹Centre for Clinical and Population Sciences, Queen's University, Belfast, Northern Ireland

²Royal Group of Hospitals, Belfast, Northern Ireland

³Division of Gastroenterology, Mount Sinai Medical Center, New York, NY, USA

⁴National Cancer Registry, Cork, Ireland

⁵St. James's Hospital, Dublin, Ireland

*Correspondence to: Centre for Clinical and Population Sciences, Queen's University, Belfast, Northern Ireland.
E-mail: m.donnell@qub.ac.uk

Abstract

Objective: To investigate strain and mental health among family caregivers of oesophageal cancer patients and possible factors associated with caregiver mental health and strain.

Methods: Patients with oesophageal adenocarcinoma in Ireland were recruited into the FINBAR study (the main aim of which was to investigate factors influencing the Barrett's adenocarcinoma relationship). Carers completed the 13-item *Caregiver Strain Index* and the *General Health Questionnaire-30* (GHQ) in the context of a brief interview with trained research staff that was undertaken separately from the interview with each cancer patient.

Results: Two hundred and twenty-seven patients participated in the FINBAR study. A total of 39 patients did not have a family carer or the carer could not be identified. Fifty percent (94/188) of carers completed the questionnaires. Mean (SD) scores for strain (6.65, SD = 3.63) and mental health status (10.21, SD = 7.30) were high and 71% of carers scored >5 on the GHQ indicating psychological distress. There was a statistically significant positive relationship between level of strain experienced by caregivers and the severity of their mental health status and whether or not carers scored >5 on the GHQ. Relatives were 1.70 (95% CI 1.34–2.15) times more likely to be defined as high scorers with each unit increase in the CSI score.

Conclusions: A significant proportion of caregivers experienced high levels of strain and psychological distress. There is a need to provide appropriate support and services targeted specifically at reducing the considerable strain of caring for patients with oesophageal cancer, particularly for carers of patients from lower socioeconomic groups.

Copyright © 2008 John Wiley & Sons, Ltd.

Keywords: cancer; oncology; oesophageal; carers; Ireland

Received: 29 May 2007
Revised: 28 November 2007
Accepted: 27 December 2007

Introduction

Increasingly, informal care is a key component of care in the community for cancer patients, complementing and substituting the care component of formal health and social services. Although there have been many patient-focused studies in cancer care as well as many studies of carers of patients with different types of mental illness or dementia, research is comparatively sparse regarding the mental health and well-being of carers and partners of cancer patients, particularly patients with oesophageal cancer and especially in Ireland.

There were, on average, a total of 445 new cases per year of oesophageal cancer in Ireland during the period 1998–2000 [1]. Oesophageal cancer is the ninth most common form of cancer in the UK [2] and the 12th most common in Ireland. The two main types of oesophageal cancer are squamous cell carcinoma and adenocarcinoma. The incidence of oesophageal adenocarcinoma has been increasing in recent decades and it is now the most

common type of oesophageal cancer in many Western countries [3–7]. Overall, oesophageal cancer has a poor prognosis. In Ireland, 5-year relative survival is 10.7% in males and 17.6% in females [1]. Surgery, in the form of a total thoracic oesophagectomy, is not suitable for all patients with oesophageal cancer, as many are elderly and have co-existing medical conditions. However, surgical resection does improve survival with up to 29% surviving 5 years or more in Northern Ireland [8]. Despite these poor survival rates, survival has been improving in oesophageal cancer patients [9] though the impact of this trend on carers is unclear and requires research attention.

Health policy is giving increasing recognition to the important role in health- and social-care systems played by informal carers who make a significant contribution towards meeting the care needs of patients. However, cancer may have adverse effects on the health of carers and to our knowledge there are no published studies of the impact on close family relatives, usually spouses or

partners, of caring for a patient with oesophageal cancer. The prevalence of mental health difficulties among carers of cancer patients varies from 20 to 50% depending on issues such as the definition of the 'difficulty' and the method of assessment; and the variables that appear to be associated with mental health difficulties such as high levels of emotional distress among carers including negative attitudes about a relative's illness, avoidance as a way of coping, relationship problems between caregiver and care receiver, gender, age, personality, support and the availability of confidant-like relationships [10]. Caring for a relative with cancer may also have positive benefits and uplifts in terms of, for example, feelings of self-worth and improved self-esteem [11].

While there would appear to be a degree of commonality between the experiences of caring for patients with oesophageal cancer and caring for patients with other types of cancer, research by, for example, Vickery *et al.* suggest that particular cancers appear to have 'a unique presentation of difficulties' [12]. Specific problems caring for oesophageal patients relate to swallowing difficulties, preparation of food and meals, 'away-from-home' eating or dining, associated rapid weight loss and debility. Oesophageal stenting may be required if curative surgery is not possible and achieving adequate calorie intake is an ongoing problem during the terminal phase [13]. In addition, carers have to deal with the fact that oesophageal cancer patients have a very poor survival [1]. Many of the investigations into the impact on carers have focused on cancers such as breast cancer with comparatively good survival and quality of life outcomes. Cases of oesophageal adenocarcinoma are predominantly male and therefore carers tend to be female. Furthermore, all patients in this study were living at home and were not receiving inpatient or hospice care (at the time that their relatives participated in the research) and we know less about the stress and strain of caring in a community or home context for oesophageal cancer patients than we do about carers of patients with other high mortality cancers. Thus, this study investigated the nature and extent of strain experienced by carers of oesophageal cancer patients, the mental health status of carers and the prevalence of carers with a General Health Questionnaire (GHQ) score >5 (and therefore deemed likely to benefit from receiving formal mental health care), and the relationship between caregiver strain and mental health status.

Method

Two hundred and forty-four patients were recruited into the factors influencing the Barrett's adenocarcinoma relationship (FINBAR) study

originally—17 patients were excluded subsequently because they did not have a primary oesophageal adenocarcinoma ($n=227$). Seventeen percent (39/227) of patients did not have a family carer ($n=7$) or the carer could not be identified ($n=32$). The sample consisted of 94 informal or family caregivers of 188 oesophageal adenocarcinoma patients who participated in the FINBAR Study. Fifty percent (94/188) of carers completed the *Caregiver Strain Index (CSI)* and the *GHQ-30* in the context of a brief interview with trained research staff following a separate interview (using the *FINBAR Patient Questionnaire*) with the member of their family who had oesophageal cancer [14].

The CSI is a brief, easy to administer set of 13 questions about the strain of caring for a relative. Respondents reply yes (scored 1) or no (scored 0) to each question and the responses are summed to give a range of scores from 0 to 13. A total score >6 is deemed to indicate marked strain and to merit attention from health- and social-care professionals. The CSI has been applied in many studies to assess the impact of caregiving on relatives of patients, including cancer patients [15]. The measure has good internal consistency and construct validity [16] and high test-retest reliability [17]. There does not appear to be a published formal analysis of the cut-off point of >6 on the CSI to indicate considerable or marked strain, though it has been used frequently in a wide range of carer studies [18] and the distribution of CSI scores in studies of carers of cancer patients suggests that the cut-off point of >6 is a conservative indicator of strain [19]. The CSI in this study achieved good internal consistency or reliability (Cronbach's alpha co-efficient: 0.85).

The GHQ-30 is a well-tested, easy-to-complete instrument. It is designed to screen for psychiatric morbidity or emotional distress and takes about 3–4 min to complete. Respondents are asked to rate the degree to which they have been feeling, for example, 'unhappy or depressed' in terms of 'not at all', 'no more than usual', 'rather more than usual' or 'much more than usual'. Half the questions indicate potential mental health problems if answered 'yes' and half indicate illness if answered 'no'. Responses may be scored using 0–1–2–3 Likert scores to indicate severity of psychological disturbance or in terms of whether or not problems are present or absent by coding replies 0–0–1–1. A score of more than 4 or 5 indicates that the respondent is likely to benefit from receiving formal mental health care. The GHQ Manual and many subsequent studies indicate good reliability and validity. In addition, the specificity and sensitivity of the GHQ-30 were estimated to be 87 and 91%, respectively, with an overall potential misclassification rate of 19% [20]. The GHQ in this study achieved a high Cronbach's alpha co-efficient of 0.95.

Table 1. Comparing the characteristics of patients whose relatives completed or did not complete the GHQ and CSI

Patient characteristics	Carers: non-respondents	Carers: respondents	P-Value
Gender			0.015
Male	106 (80%)	86 (91%)	
Female	27 (20%)	8 (9%)	
Age (years)	65.3	62.8	0.104
Education (years)	10.5	10.9	0.238
Total thoracic oesophagectomy			0.474
No	63 (47%)	50 (53 %)	
Yes	66 (50%)	43 (46%)	
Unknown	4 (3%)	1 (1%)	

Table 2. Descriptive statistics relating to CSI and GHQ completed by carers

	CSI	GHQ
Mean (SD)	6.65 (3.63)	10.2 (7.30)
Median	7	0
Mode	7, 9	0
Range	0–13	0–30
Potential range	0–13	0–30
Number (%) of carers scoring above	CSI	GHQ
4	66/93 (71%)	72/94 (77%)
5	59/93 (63%)	67/94 (71%)
6	57/93 (55%)	64/94 (68%)
7	39/93 (42%)	57/94 (61%)

A recommended cut-off score > 6 on the CSI indicates 'marked strain'; and a cut-off score of 4 or 5 on the GHQ-30 indicates psychological distress and that a person with this score or higher would be likely to benefit from receiving formal mental health services.

Analysis

In addition to undertaking a descriptive statistical analysis, regression analysis was used to examine the relationship between variables (e.g. the gender of the carer, the gender, age, years of full-time education and main type of job (manual/non-manual) of the patient and whether or not the patient had an oesophagectomy (i.e. surgery to remove the oesophagus)) and the main outcome variable (mental health status or psychological distress). A logistic regression analysis, adjusted for the aforementioned variables, was used to investigate high vs low GHQ scoring carers using a cut-off point of > 5 .

Results

The majority of carers were female (78/94; 83%); only nine carers were male (mostly husbands)—information about gender was unavailable for seven carers. Almost 80% (75/94) were wives (62), female partners (8) or daughters (5) of oesophageal cancer patients; 14% (13/94) were non-partner carers such as adult children. The mean average age (range) of all oesophageal patients recruited into the FINBAR study was 64 (34–85) years and the mean average duration (range) between diagnosis and research interview was 108 (3–329) days. Differ-

ences between relatives who responded ($n = 94$) and relatives who did not respond ($n = 133$) in terms of respective patient group characteristics are presented in Table 1. The relatives of males were significantly more likely to have taken part in the study compared with relatives of females.

The results presented in Table 2 show that carers had high mean average scores for both measures and significantly high proportions scored above the threshold indicating marked strain (57/93; 55%) and poor mental health status (67/94; 71%). The proportion of carers with poor mental health is high even when more conservative cut-off points are applied. Carers of patients who received their diagnosis relatively recently (within the six months preceding the research interview) had, on average, higher (though not statistically significant) GHQ-30 scores than carers of patients who had received their diagnosis more than six months ago (Mean (SD) scores: 12.73 (6.97) vs 10.66 (7.44), $p = 0.773$).

Statistically, significantly higher proportions of carers with GHQ scores > 5 recorded that they experienced each type of caring-associated strain. The most frequently endorsed types of strain noted by high GHQ scorers (compared with low GHQ scorers) included emotional adjustments due to the caring role (97% vs 62%), financial strain (80% vs 20%), time demands (80% vs 36%), feeling overwhelmed (77% vs 39%), disturbed sleep (77% vs 31%) and feeling confined (73% vs 12%). Only

Table 3. Relationship between being a high GHQ-30 scorer (> 5) and strain as indicated by answering 'yes' to each item on the Caregiver Strain Index

Type of strain (CSI item) associated with caring	Number (%) of responding 'yes'				
	High scorer	Low scorer	Adjusted ^a odds ratio	95% CI	P-Value
Sleep disturbed	26 (31)	65 (77)	10.0	2.96–33.94	<0.001
Inconvenient	24 (13)	64 (44)	7.15	1.40–36.46	0.018
A physical strain	26 (3)	64 (18)	15.70	1.72–143.26	0.015
Confining	26 (12)	63 (73)	47.78	7.16–318.86	<0.0001
Family adjustments	25 (24)	64 (67)	18.90	3.74–95.44	<0.0001
Changes in personal plans	25 (36)	64 (66)	3.53	1.10–11.31	0.034
Time demands	25 (36)	64 (80)	11.02	2.95–41.14	<0.001
Emotional adjustments	26 (62)	66 (97)	19.31	3.22–115.76	0.001
Behaviour upsetting	26 (15)	63 (56)	11.00	2.53–47.91	0.001
Patient has changed	26 (23)	65 (55)	4.87	1.42–16.65	0.012
Work adjustments	25 (24)	63 (48)	3.51	0.96–12.86	0.058
Feeling overwhelmed	26 (39)	66 (77)	14.67	3.57–60.27	<0.001
Financial strain	26 (19)	63 (80)	8.85	2.59–30.28	0.001

^a All analyses were adjusted for the gender of the carer, the gender, age, years of full-time education, job type (manual/non-manual) of the patient and whether or not the patient had an oesophagectomy.

relatively small proportions of cases and non-cases considered caring to be a physical strain (18% vs 3%), inconvenient (44% vs 13%) or requiring work adjustments (48% vs 24%).

Table 3 summarises the results of a logistic regression analysis that was conducted in order to investigate associations with being a high GHQ scorer vs being a low scorer (as measured by a cut-off score of 5 on the GHQ-30). Relatives were 1.70 (95% CI 1.34–2.15) times more likely to be defined as high scorers with each unit increase in the CSI score. A comparison of high and low GHQ scorers, mutually adjusted for each available variable, resulted in the following odds ratios, 95% confidence intervals and probability values: (a) gender of carer (reference group—male): 3.32, 0.67–16.57, 0.143; (b) gender of patient (reference group—male): 0.42, 0.08–2.32, 0.323; (c) job type of patient (reference group—non-manual): 6.22, 1.68–23.06, 0.006; (d) education of patient (continuous variable—years): 0.95, 0.76–1.19; (e) age of patient at interview (continuous variable—years): 0.95, 0.98–1.00, 0.052; (f) resection (reference group—no resection): 0.64, 0.24–1.75, 0.386. Carers of patients who undertook manual jobs appeared to be more likely to be high GHQ scorers (indicating poorer mental health status), as did carers of patients who were older.

Discussion

Mental health status

Assessing the mental health and strain of carers of oesophageal cancer patients rather than caregiving *per se* was the main focus of this study. The psychological well-being or mental health status of carers of oesophageal cancer patients was poor and

significantly worse compared with carers of other groups of patients [21–23]. These findings together with other research [24,25] indicate that cancer, particularly this type of cancer, impacts significantly on relatives as well as patients. The GHQ-30, unlike other versions of the GHQ, does not contain the somatic items or symptoms from the full GHQ-60. Thus, the use of the GHQ-30 affords some control over the propensity by other versions of the GHQ to produce artificially inflated case rates due to the fact that older respondents tend to report various kinds of physical health-related problems. However, it is important to note that the GHQ-30 has a potential misclassification rate of almost 20% regarding the identification of people who are deemed to have a level of psychological distress requiring intervention by mental health services.

Carers of oesophageal cancer patients appear to have comparable levels of distress and strain as carers of palliative-care patients. For example, one study [24] found that 84% of informal carers in palliative cancer care scored above the GHQ threshold indicating poor mental health and 41% reported high levels of strain related to caregiving (as measured by CSI). Low socioeconomic background and age appeared to be the only statistically significant variables that were associated with the chances of a carer being a high GHQ scorer. The same associations have been reported in other studies though there appears to be some degree of inconsistency between studies [10]. It is worth noting that most of the carers in this study were women and that previous research indicates that, overall, female informal carers report higher levels of psychological distress than male carers [25] and that elevated levels of distress tend to persist over a longer period of time for women compared with men [26]. Longitudinal research is required to

elucidate potential pathways between mental health status and strain. The lack of medical data is a weakness of the study presented here and it is important to bear this point in mind when considering the results. Future studies should incorporate key medical variables.

Caregiver strain

Carers also reported that they experienced a high level of mainly 'subjective' or emotional-related sources of strain (rather than 'objective' strain from the physical demands of caring). One study [27] found that spouse carers of patients with laryngeal cancer had a moderate level of strain (mean CSI score: 5.1) though a subgroup comprising spouses of patients who had received their diagnosis in the previous six months had a mean score of 7.4 indicating a high level of caregiver strain. Unsurprisingly, perhaps, a particularly difficult stage for carers seems to occur during the first six months with feelings of strain lessening over time to a mild to moderate level. For example, carers in the study noted above [27] reported a mean CSI score of 4.2 at a 3-year follow-up point. It is important to note that laryngeal cancer has a high survival rate unlike oesophageal cancer. There are no longitudinal studies of carers of patients with oesophageal cancer as far as we are aware. Almost 80% of carers of patients in the study presented here received a diagnosis within the six months prior to the research interview date and their levels of strain and mental health were significantly poorer than carers whose relatives had known about their diagnosis for a longer period of time. Clearly, the period immediately after diagnosis is qualitatively different to the period several months post-diagnosis.

These findings suggest that focused support and separate appropriate attention should be targeted at carers very early in the care pathway, particularly in the initial stage of diagnosis with ongoing support based on assessed need provided to carers of survivors. For example, use of support groups and brief counselling specifically for carers may help to 'buffer' the impact of the diagnosis and the experience of caring for relatives.

Conclusions

This study provides important information for health-care planners and professionals working with patients of oesophageal cancer and their relatives. For example, oncology staff such as doctors, nurses, social workers and psychologists may improve the quality of care for patients and relatives and the quality of their lives by assessing them as a 'unit' (given that the majority of patient-carer dyads comprise married couples and research

with carers of other patient groups such as dementia indicate that 'live-in' carers have higher levels of strain and distress than carers who live outside the patient's home [28]). Service responses to assessed need such as support groups, information sessions (e.g. offering financial advice) and brief counselling and generally involving relatives in the care planning arrangements may help to reduce the high level of strain and stress experienced by carers as well as alleviating concerns that patients may have about their relatives.

The study presented here, which took place in the context of a larger case-control study designed to address specific hypotheses [14], was an exploratory attempt to identify, assess and describe the level of strain and psychological distress or morbidity and associated factors among carers of oesophageal cancer patients. The study focuses on the lack of research attention given specifically to carers of oesophageal cancer patients and does not present an exhaustive review and discussion of the literature on caregiving and caregiving strain of cancer patients. There was not an opportunity to design a theoretically driven subsidiary study of carers and necessarily it was possible to use only a few brief measures. However, currently, a follow-up study of carers guided by relevant theoretical models [29–31] is being planned to investigate the transient or chronic nature of poor psychological health of oesophageal cancer survivors, the processes of adjustment and adaptation (including an assessment of the positive and negative effects of caring and possible interactive or moderating effects) and experiences of access to and receipt of appropriate services and supports. In addition, there are few longitudinal studies of carers and, therefore, the potential longer-term impact of caring for cancer survivors including the small but increasing number of oesophageal cancer survivors is relatively unknown.

Overall, early findings suggest that service responses should revolve around a consideration in tandem of the health needs of patients and carers and the demands of caring. It may be important to note that the extent to which the sample of carers may be representative of the entire population of relatives who provide informal care for oesophageal cancer patients is unclear though an analysis of the limited comparative data on respondents and non-respondents revealed only one significant difference—female carers (over 80% of the sample) were more likely to take part in the study than male carers. In addition, the small sample size and relatively moderate response rate limit the power of the multivariate analysis. Finally, while the deleterious effects of caring are a major public health concern, it is worth noting that increasingly research indicates that many carers report positive benefits and experiences as a result of their caring role [32].

Acknowledgements

We appreciate the contributions made by the study participants and their families. We would like to thank the clinicians who were contacted throughout the study period and their secretaries for administrative support. Thanks also to the research team including Siobhan Reynolds, Majella Gallagher, Carol Anderson and Martin McAnaespie and to Dr Damian McManus for the help in classifying the tumour sites. Thanks to the Northern Ireland Cancer Registry and National Cancer Registry Ireland for their support and involvement in the research. An Ireland–Northern Ireland Co-operation Research Project Grant sponsored by the Research & Development Office, Belfast, and the Health Research Board Dublin and by the Ulster Cancer Foundation, Northern Ireland, funded the FINBAR study.

Ethical committee approval for the FINBAR study was obtained from the Research Ethics Committee of the Queen's University Belfast, the Clinical Research Ethics Committee of the Cork Teaching Hospitals and the Research Ethics Committee Board of St. James's Hospital, Dublin. There are no known conflicts of interest.

References

- Campo J, Comber H, Gavin AT. *All-Ireland Cancer Statistics 1998–2000*. Northern Ireland Cancer Registry and the National Cancer Registry, 2004.
- Cancer Research UK. Website downloaded in April 2007 <http://www.cancerhelp.org.uk/help/default.asp?page=4478>
- Hansson LE, Sparen P, Nyren O. Increasing incidence of both major histological types of esophageal carcinomas among men in Sweden. *Int J Cancer* 1993;**54**(3): 402–407.
- Botterweck AA, Schouten LJ, Volovics A, Dorant E, van Den Brandt PA. Trends in incidence of adenocarcinoma of the oesophagus and gastric cardia in ten European countries. *Int J Epidemiol* 2000;**29**(4): 645–654.
- Powell J, McConkey CC. The rising trend in oesophageal adenocarcinoma and gastric cardia. *Eur J Cancer Prev* 1992;**1**(3):265–269.
- Moller H. Incidence of cancer of oesophagus, cardia and stomach in Denmark. *Eur J Cancer Prev* 1992;**1**(2): 159–164.
- Blot WJ, McLaughlin JK. The changing epidemiology of esophageal cancer. *Semin Oncol* 1999;**26**(5 Suppl. 15):2–8.
- McManus K, Anikin V, McGuigan J. Total thoracic oesophagectomy for oesophageal carcinoma: has it been worth it? *Eur J Cardiothorac Surg* 1999;**16**(3):261–265.
- Sundelof M, Ye W, Dickman PW, Lagergren J. Improved survival in both histologic types of oesophageal cancer in Sweden. *Int J Cancer* 2002;**99**(5):751–754.
- Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer* 2003;**39**:1517–1524.
- Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos G. Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer* 2000;**86**:577–588.
- Vickery LE, Latchford G, Hewison J, Bellew M, Feber T. The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head Neck* 2002;**25**:289–296.
- Kirby JD. Quality of life after oesophagectomy: the patients' perspective. *Dis Esophagus* 1999;**12**:168–171.
- Anderson LA, Johnston BT, Watson RGP *et al.* Nonsteroidal anti-inflammatory drugs and the esophageal-metaplasia-adenocarcinoma sequence. *Cancer Res* 2006;**66**(9):4975–4982.
- Schumacher KL, Dodd MJ, Paul SM. The stress process in family caregivers of persons receiving chemotherapy. *Res Nurs Health* 1993;**16**:395–404.
- Robinson BC. Validation of a caregiver strain index. *J Gerontol* 1983;**38**:344–348.
- Thornton M, Triviss SS. Analysis of the reliability of the modified caregiver strain index. *J Gerontol B Psychol Sci* 2003;**58**(2):S127–S132.
- Wilkinson PR, Wolfe CDA, Rudd AG, Ross-Russell RW. A long-term follow-up of stroke patients. *Stroke* 1997;**28**:507–512.
- Miaskowski C, Kragness L, Dibble S, Wallhagen M. Differences in mood states, health status and caregiver strain between family caregivers of oncology outpatients with and without cancer-related pain. *J Pain Symptom Manage* 1997;**13**:138–147.
- Goldberg D, Williams P. *Manual of the General Health Questionnaire*. NFER Publishing: Windsor, England, 1988.
- Ulstain I, Wyller Bruun T, Engedal K. High score on the Relative Stress Scale, a marker of possible psychiatric disorder in family carers of patients with dementia. *Int J Geriatr Psychiatry* 2007;**22**:195–202.
- Blake H, Lincoln NB, Clarke DD. Caregiver strain in spouses of stroke patients. *Clin Rehabil* 2003;**17**: 312–317.
- Mooney E, McNeill M. *Informal Carers Report: A Report from the Health and Social Well-being Survey*. DHSSPS: Belfast, 2001.
- Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *Palliat Med* 1999; **13**:37–44.
- Hagerdoon M, Buunk BP, Kuijer RG, Wobbes T, Sanderman R. Couples dealing with cancer: role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology* 2000;**9**:232–242.
- Tuinstra J, Hagedoon M, Van Sonderen E *et al.* Psychological distress in couples dealing with colorectal cancer: gender and role differences and intracouple correspondence. *Br J Health Psychol* 2004;**9**:465–478.
- Blood GW, Simpson KC, Dineen M, Kauffman SM, Raimondi SC. Spouses of laryngeal cancer: caregiver strain and burden. *J Commun Disord* 1994;**27**:19–35.
- Schulz R, O'Brien AT, Bookwala J, Fleissner. Psychiatric and physical morbidity effects of dementia care giving: prevalence, correlates and causes. *Gerontologist* 1995;**35**:771–779.
- Leventhal SJ, Helgeson VS. Social constraints, intrusive thoughts and mental health after prostate cancer. *J Soc Clin Psychol* 1998;**17**:89–106.
- Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;**30**:583–594.
- Gilbar O, Ben-Zur H. *Cancer and the Family Caregiver*. Charles C. Thomas Publisher: Springfield, IL, USA, 2002.
- Cohen CA, Gold DP, Schulman KL *et al.* Positive aspects in care giving: an overlooked variable in research. *Can J Aging* 1994;**94**:378–391.